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Title of the article:

"I think maybe 10 years seems a bit long." Beliefs and attitudes of women who had never used intrauterine contraception

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## Abstract

**Aim:** To explore, in general practice settings the concerns, beliefs and attitudes about intrauterine contraception reported by women, who had never used the methods.

**Method:** We used a sequential mixed-method (QUAL/quant) approach. A pragmatic, self-selecting sample of thirty women, aged 18-46 years, who had never used intrauterine contraception (IUC), was recruited through seven general practices in South East England. Themes arising from qualitative interviews were used to construct a quantitative survey, completed by a pragmatic sample of 1195 women, aged between 18-49 years, attending thirty-two general practices in the same region, between February and August 2015.

**Findings:** Qualitative themes were concerns about the long acting nature of IUC, concerns about bodily boundaries, and informal knowledge of IUC, especially “friend of a friend” stories. Women were not sure if the devices could be removed before their full 5 or 10 year duration, and felt that these timeframes did not fit with their reproductive intentions. Quantitative survey data showed that the most commonly endorsed concerns among never-users were painful fitting (55.8%), unpleasant removal of the device (60.1%), and concern about having a device ‘inside me’ (60.2%).

**Conclusions:** To facilitate fully informed contraceptive choice, information provided to women considering IUC should be tailored to address the concerns expressed by never-users, particularly around the details of insertion and removal, and concerns about adverse long-term effects of the device.

Women need to be reassured that IUC can be removed and fertility restored at any time following insertion.

# “I think maybe 10 years seems a bit long”: beliefs and attitudes of women who had never used IUC

## Introduction

Intrauterine contraception (IUC) is a highly effective, safe long-acting reversible contraceptive (LARC) method which is available without cost to women in the United Kingdom (UK), the majority of whom access contraception through general practices. Both intrauterine devices (IUD) and intrauterine systems (IUS) have typical failure rates of less than 1%, compared to failure rates of 9% and 18% for the oral contraceptive pill and male condom respectively [1].

In 2005 the National Institute for Health and Care Excellence (NICE) recommended increased use of LARCs for all women seeking contraceptive advice because of their cost effectiveness and low failure rates[2]. Since then the increase in LARC use in the UK has mostly been accounted for by an increase in the uptake of contraceptive implants, and not by intrauterine contraception [3]. Intrauterine devices (IUD) and intrauterine systems (IUS) are the longest-acting of the LARC methods, lasting up to 10 years and 5 years respectively. In addition copper IUDs are a hormone-free method. The attributes of high efficacy and long duration make these methods appear to be good choices for women.

However, statistics indicate that only a minority of women who require contraception choose IUC in the UK [4,5 ], despite dominant medical discourse viewing these methods positively because of their long-acting nature, low failure rates and ‘fit and forget’ qualities[2]. This discordance between medical opinion and the choices made by women is important to understand.

Negative attitudes towards intrauterine contraception have been extensively reported in the literature. Women express concerns about the risks and side effects of IUC [6-17], about painful fitting and unpleasant removal [6-8, 10-14] and are strongly influenced by adverse accounts of other people [6, 7 14, 16, 17]. The majority of women in the UK access contraception through their general practice: [18]. For this reason it is relevant to explore the attitudes of women beyond the specialist contraceptive clinic setting. The most recent published research looking at the views of women who were not IUC users, recruited from general practice in the UK, found that they were anxious about IUC fitting, lacked objective knowledge about IUC, viewed an internal device as unhygienic and an infection risk, disliked the lack of control over its action compared to short-acting methods, and distrusted its effectiveness [6]. Since this research was carried out more than a decade ago, NICE recommendations [2] and the introduction of a Quality Outcomes Framework (QoF) payment encouraging GPs to advise women on LARC methods in 2009, should have resulted in women becoming better informed about intrauterine contraception [19]. We therefore set out to use qualitative interviewing to explore in some depth the attitudes and beliefs of women who had never used IUC. In order to address the limitations of qualitative methods in terms of representativeness, we used a sequential mixed method approach, which involved a subsequent quantitative survey, based on the qualitative themes, to indicate whether these attitudes were also evident in a larger sample.

## Methods

Our research study used a four arm sequential mixed-method approach to produce qualitative and quantitative data from both practitioners and patients in general practice. Sequential mixed-methods are increasingly used in health care settings,

where qualitative findings can be used to explain quantitative data (QUANT/qual) or qualitative findings are drawn on to devise quantitative surveys, whose data can help to indicate how representative the qualitative findings are in the wider population (QUAL/quant) [20-27]. The patient arm of the study reported in this paper adopted a QUAL/quant approach, in which qualitative interviews were carried out first, and these interviews were used to inform a questionnaire which was distributed to a larger sample of women.

#### Convergence of Qualitative and Quantitative Data

Qualitative methods can provide rich data but cannot give any indication of how the views might express opinions held in a wider population. This paper uses the quantitative survey data to indicate to what extent the views of the participants in the qualitative study are endorsed by a wider and unrelated sample of women from the same region.

Ethical approval for this project was obtained from NRES Committee London South East (14/LO/0004).

#### Qualitative Arm

A pragmatic, self-selected, sample of thirty women, aged 18-45 years, who had never used IUC, was recruited through seven general practices in the South East of England. Potential participants were invited to take part in the research by the GP or staff member seeing them and given an information sheet. If they expressed an interest in the study and self-reported that they had never used IUC, they were asked to complete a consent form to share their contact details with the research team. Their details were then passed on to the researcher (VN), who contacted the women by email or telephone to arrange an interview. The interviews took place at a venue

that was convenient for the women or over the telephone, depending on participant preference. Participants were given a £20 high street voucher as an acknowledgment of their time and contribution. Consenting participants were interviewed about their views and opinions on IUC in order to explore the concerns that they had about the method (See Supplementary File 1 for Interview Schedule). The interviewees ranged in age from 19-45 years and all, except two, identified as White British (See Supplementary File 2 for demographic table).

The qualitative interview data were analysed using a form of thematic analysis in which the findings are grounded in research participants' accounts [28]. First the data were broad-coded and a coding frame devised through discussion between two researchers. The transcripts were then coded into emerging themes. Each emerging theme was then fine-coded. To ensure rigour, the first researcher's interpretation of the data was compared against that of the second researcher and any differences resolved through discussion. To help facilitate analysis the researchers utilised the data management software package NVivo (QSR International Pty Ltd. Version 10, 2012).

#### Quantitative Arm

Themes arising from the interviews were used to construct a quantitative survey, which was distributed to a pragmatic sample of women (users and non-users of IUC), aged between 18-49 years, attending a sample of thirty-two general practices in the same region, between February and August 2015, regardless of the reason for their attendance (see Supplementary File 3 for Survey). All women between 18 and 49

years attending the practices within the timeframe of the research project, were invited to take part, either personally by a practice staff member or research nurse, or through posters and information screens in the practice waiting area. Our sample size calculation required a minimum of 1068 women (See Supplementary File 4 for details). Of 4300 questionnaires distributed, 1244 questionnaires were returned, indicating a response rate of 28.9%. Removing blank questionnaires and respondents who were outside the intended age range (18-49 years) resulted in 1195 responses for analysis [29].

The survey asked for demographic data, opinions, experiences and knowledge of intrauterine contraception, current contraceptive method, and level of agreement with statements of concern about IUC, derived from the qualitative interviews (Supplementary File 3). The survey was piloted before use with two separate groups of students (undergraduate and postgraduate) in a higher educational establishment and wording of the items was altered according to their feedback on acceptability and clarity.

Descriptive quantitative analysis was carried out using SPSS (IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp).to summarise attitudes to IUC and demographic characteristics



## Results

### Qualitative Findings

The primary descriptive themes arising from the interview data with 30 women who had never used IUC were;

- the long term nature of IUC,
- adverse effects of IUC,
- lack of control over starting and stopping the method,
- concerns about fitting and removal,
- the imagined size and shape of the device and its method of action,
- the internal nature of the device,
- the device moving, falling out or being felt by a partner,
- 'friend of a friend' reports from other people.

These basic themes are combined into 3 overlapping conceptual areas;

Contraceptive timeframes, Body boundaries and Informal knowledge, as illustrated below (Table 1).

<b>Table 1 Analysis of Qualitative data</b>	
<b>Conceptual area</b>	<b>Primary Themes</b>
Contraceptive timeframes	<ul style="list-style-type: none"><li>• the long-term nature of IUC</li><li>• lack of control over starting and stopping the method (concerns about accessing early removal)</li><li>• adverse effects of IUC (device becomes unclean or deteriorates over time)</li></ul>
Body boundaries and a device "inside me"	<ul style="list-style-type: none"><li>• concerns about fitting and removal (need for health care</li></ul>

	<p>practitioner to fit/remove; pain; method of fitting)</p> <ul style="list-style-type: none"> <li>the internal nature of the device ('foreign object')</li> </ul>
Informal knowledge	<ul style="list-style-type: none"> <li>the imagined size and shape of the device and its method of action ('barbaric looking', 'scrapes away')</li> <li>the device moving, falling out</li> <li>worries about device being felt by partner</li> <li>'friend of a friend' reports from other people.</li> </ul>

#### Contraceptive timeframes

Dislike of the long-term nature of the device was expressed by interviewees. (All names used are pseudonyms).

Responses suggested that this concern arose from three sources. The first was the view that 5-10 years of contraception was too long a period of time to commit to contraception. This was compounded by a lack of confidence that the device could be removed at any time, and at the women's request. There was also concern about the effects of having a device within the body for a prolonged period of time. In referring to the timeframe of the IUD Carly told us:

*The only thing I think maybe 10 years seem a bit long.[...], five years would have been enough for me but it would have made sense to still have it fitted and I'm still two or three years away from having children myself anyway so ...*

Here she is placing her need for contraception within the wider context of her mid-term life plans and hopes.

Other time-related concerns referred to uncertainty about whether the device could be removed easily on request, and fertility returned, sooner than the 5 or 10 years of its duration. Other research has also highlighted that discontinuing with LARC is not as simple as ceasing to take the pill [30]. Linda expresses this concern:

*I did ask the doctor about it. But then like sort of worried because I'm sure that when I spoke to the doctor she said that you'd have to have it in there for so long [...] if I thought I could just put it in and take it out I think I would have given it more thought, but it felt like it wasn't something that you could just have put in and have taken out. It felt like there was a bit of a timeframe that you had to have it in for.*

Connected to the longevity of the method was also a concern about the imagined harmful effects of an internal device within the body for a prolonged time, related to the cyclic nature of the female body and ideas about uncleanliness and bodily pollution from a hidden device. Adele told us: *if you were to have your period it might all get a messed up and... yeah, I wouldn't like... if I was to think about it, I would feel like it is all a bit unclean inside[...]I'd be worried that it's not clean. I want it changed regularly. I don't know if you can do that.*

#### *Body Boundaries and a device "inside me"*

The internal nature of IUC was experienced by many women as a potential loss of control over their body and its fertility, especially where adverse effects were experienced. For Amy, personal autonomy over her contraceptive method was important, and this was something that she felt she would lose in selecting an IUC:

*“So I think there’s also that worry that with the coil I can’t really control it. I know I’d be able to go to the doctor and get it removed, but it’s just the fact that you can’t control it, if that makes sense?”*

In addition to displaying a lack of knowledge and voicing anxieties about IUC fitting and removal, never-users expressed concerns about the breaching of body boundaries. The thought of fitting and removal, and of associated pain, was off-putting for Linda:

*“Yeah, it sounds very painful to have it fitted and to have it removed [...] Yeah, I think that, yeah – and the removal of the coil really does put me off, and the fitting too.”*

Amy was concerned with how invasive the process of fitting might be:

*“No, basically the reason I didn’t consider it was because I think you have to have an operation. I don’t know if that’s right – not an operation but you’re put to sleep and I don’t know that much about it to be honest.”*

Women, such as Lisa expressed concerns about IUC being a ‘foreign object’ ‘inside me’, a response echoed by over 60% of survey respondents:

*“I just don’t like the idea of having a piece of metal or whatever it is inside my womb. I just didn’t want it.”*

### Informal knowledge

Women were often misinformed about aspects of IUC and unclear about how it acted within the body. “Friend of a friend” stories were reported as influential in forming an opinion of IUC. Amongst women who had never used IUC, there was lack of knowledge about the size and shape of the device. These imaginings related to what IUC might look like, and how it might ‘feel’ once it was in place. As in Ellen’s account below, participants’ language related to images of the coil as potentially damaging:

*“I think you imagine it’s going to be a giant spring (laughs) that is sort of placed inside you and it’s going to be a bit uncomfortable and could cause a bit of discomfort during sex, I think that’s part of what puts women off. They just have this idea because of the name of it it’s going to be something almost a bit barbaric looking.”*

Descriptions of the action of IUC also indicated concerns about IUC as harmful. In Linda’s view this was connected to erroneous beliefs about how IUC prevents pregnancy:

*“It’s imagining what the coil is doing, so you sort of visualise it just scraping away at your, the wall of your uterus. (Laughter) And it just makes me think of a little bottle brush in there just scraping off all your, the wall of the uterus to prevent any ovary embedding and I suppose the image in your mind is it’s sort of like some little metal spring around scratching away at your uterus.”*

Some participants were concerned that the device could move or fall out, or that the device might be felt by their sexual partners during intercourse:

Gail *“Maybe it could come out or slip down or not be where it’s supposed to be.”*

As is evident in the examples below, many of the concerns expressed comprised 'friend of a friend' stories, a narrative circulated among a social group and shared as a means of exploring risk, and which are powerful in affecting opinion [30]:

*Lisa "I have a friend that had one for about five years and when she had it removed it was like ripping out her womb lining, and that sounds horrific. And also I've heard of like a friend of a friend who had really bad endometriosis and she basically contracted out her coil in the toilets of a nightclub, and I just don't want that."*

### Quantitative Findings

The quantitative sample did not differ significantly in terms of age bands from the GP female population of England but differed from the 2011 Census ethnicity distribution because it had a lower proportion of Asian and black respondents than in the overall population of England and Wales. [31, 32 ] (see Supplementary file 4). This larger sample, of both ever- and never-users, was surveyed to indicate how typical the attitudes expressed by qualitative participants were, in a larger sample of women attending general practices. Only the views of never-users are reported here.

Survey respondents were asked to what extent they agreed or disagreed with concerns derived from the qualitative interviews, using visual analogue scales (VAS). Respondents are categorised as endorsing a concern if they 'agree' or 'strongly agree' with it.

The views of 873 never-users (73% of total survey respondents) are reported here to indicate the typicality of the reported qualitative findings above in a larger sample (Table 2).

Table 2 Survey Responses			
Concern	Response	N=873	
		n (%)	95%CI
I don't like the thought of having something like that inside me	Agree or strongly agree	526 (60.2%)	57.0-63.4%
I worry that removal of a copper coil or Mirena would be unpleasant	Agree or strongly agree	525 (60.1%)	56.8-63.3%
The fitting of a copper coil or Mirena would be painful	Agree or strongly agree	487 (55.8%)	52.5-59.0%
I worry that it will move inside me	Agree or strongly agree	404 (46.3%)	43.0-49.6%
I worry that it will damage my womb	Agree or strongly agree	345 (39.5%)	36.3-42.8%
I worry that my partner will feel it during sex	Agree or strongly agree	311 (35.6%)	32.5-38.9%
I worry that if I got pregnant ... it might damage the baby	Agree or strongly agree	293 (33.6%)	30.5-36.8%
I worry that it will make it harder to get pregnant in the future	Agree or strongly agree	252 (28.9%)	26.0-32.0%
I worry that it will fall out	Agree or strongly agree	241 (27.6%)	24.7-30.7%
Having to have a copper coil or Mirena fitted would be embarrassing	Agree or strongly agree	213 (24.4%)	21.7-27.4%
I don't like having to ask a nurse or doctor to remove it	Agree or strongly agree	196 (22.4%)	19.8-25.3%
Having to make a special appointment for fitting puts me off	Agree or strongly agree	182 (20.8%)	18.3-23.7%
The experiences of other people that I know when using a copper coil	Bad or v. Bad	170 (19.5%)	17.0-22.2%
The experiences of other people that I know when using Mirena have been	Bad or v. Bad	99 (11.3%)	9.4-13.6%
I think the fact that copper coils and Mirena are long-acting is	Bad or v. Bad	54 (6.2%)	4.8-8.0%

The primary themes from our qualitative data were therefore well represented in the quantitative data. Dislike of the internal nature of the device was the most endorsed statement, with 60.2% of survey respondents agreeing or strongly agreeing with the theme. Concerns about fitting and removal expressed by the qualitative participants were endorsed by 60.1% (removal) and 55.8% (fitting) of the quantitative survey respondents. The potential for the device moving (46.3%), being felt by a partner (35.6%) or falling out (27.6%) were present in the survey data. Concerns about adverse effects of IUC are also endorsed by the quantitative data including concerns about womb damage (39.5%) and about the device affecting future fertility (28.9%). Adverse reports from other people about IUC were reported by 19.5% (IUD) and 11.3% (IUS). A small number (6.2%) of survey respondents reported that the long acting nature of IUC was a 'bad or very bad' feature.

## Discussion

This research presents a complex picture of the concerns of never-users regarding IUC, and adds significantly to a body of knowledge about the influence of adverse accounts of IUC from other people [6,7,14,16,17]; concerns about the risks and side effects of IUC [6-14,16,17]; and about painful fitting and unpleasant removal [6-8,10-14], fears about the device moving [10], and being viewed as a foreign body over which the user has no control [11,33]. The mixed method design allowed us to indicate the extent to which views expressed in qualitative interviews reflect attitudes in a larger sample, and it is notable how persistent these concerns are in the population over time, despite efforts to provide objective and reassuring information about IUC.

Concern about the effectiveness of IUC was not an overt issue in our sample compared to other studies [8, 9, 16].



We are also able to contribute to resolving an area of uncertainty in the evidence-base. Although a systematic review by Coombe et al. [34] found that longevity was reported by women as one of the top positive characteristics of IUC, our research shows that the long-acting nature of the method is not seen as an advantage by all women. This is a finding shared by previous research [8, 12] Our study provides new insights into why some women appear to be opposed to the method because of its potentially long duration of use. Previously published quantitative analysis of this sample, contrasting the views of women who had never used IUC with those who had 'ever' used IUC, has shown that regarding the long acting nature of IUC as a negative feature predicts non-use [29]. In the context of medical discourse and information-giving which present the long duration of IUC as a very positive feature, this uneasiness regarding the long-acting nature of IUC is important. Our research indicates that women who had never used IUC had three separate concerns about the long-acting nature of the method - a lack of confidence that the device could be removed quickly and that fertility would be unaffected, disquiet about the health effects of having a foreign object in the body for a prolonged period of time, and the view that 5-10 years was too long to commit to a method. Pregnancy intentions, and beliefs about when pregnancy might be desirable in the context of the life-course, influenced views on the appropriateness of long-term methods.

We believe that the various anxieties expressed by never-users about IUC require a nuanced and varied approach by practitioners. Facilitating rapid and easy removal when requested, and taking time to reassure women that removal can take place after any duration of use, may alleviate concerns about needing to request removal. Some of the concerns which never-users express, such as misconceptions about the size and shape of IUC, its method of action, how it is fitted and removed, and the effects of a long lasting device in the body, can be addressed by better factual

information provision, although previous research suggests that factual information alone may not be enough to change attitudes [8, 33]. We suggest that practitioners advising women on contraception, especially in the context of the QoF requirement to discuss LARC methods, should be aware of the concerns expressed by our sample and take proactive steps to enquire about anxiety about these issues. We are working on producing an aide-memoire for practitioners who advise women on contraception to act as a reminder of the concerns which may need to be explicitly addressed.

Accounts of other people's bad experiences of IUC are prominent in the interviews of never-users of IUC, and are reported to be influential in decisions about using IUC. The effect of a positive, personal account of IUC, including an account from a healthcare provider, has been reported previously [14-16]. In tandem with our findings about the adverse influence of negative personal accounts, this suggests that unmet informational needs regarding IUC could be addressed in innovative ways which involve a more personal and subjective narrative or medium.

#### [Limitations of this research](#)

The qualitative arm of this project was carried out in a specific geographical area of England using a self-selected sample of participants. To this extent, and in common with the non-generalisability of the qualitative method, we cannot claim that the views expressed are representative of the population in general. Our quantitative sample, although larger, was also self-selected and therefore might not be representative of the population as a whole.

We did not gather socio-economic data from either our quantitative or qualitative samples, and we only had a limited number of participants from ethnic minority backgrounds, particularly in the qualitative sample. This is a limitation, since ethnicity and socio-economic status may influence attitudes about, and knowledge of, IUC [15].

## Conclusions

Women need to be reassured that IUC can be removed and fertility restored at any time following insertion. This should be explicitly stated in information leaflets on IUC. More research is needed to understand the personal and reproductive timeframes which influence contraceptive choice and the acceptability of long-acting methods in terms of their duration and when pregnancy is intended.

We have found that concerns and misinformation persist about IUC, 8 years after the last research on this topic in this population [6, 8] and 10 years after the NICE guidelines encouraged more advice for women about LARC methods in the UK [2]. Information provided to women considering IUC should be innovatively constructed and tailored to address the concerns expressed by never-users more fully, particularly around the details of insertion and removal, the choice to remove the device at any stage after insertion, and concerns about potential adverse long-term effects.

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**Contributors:**

Susan Walker contributed to the design, data collection, data analysis and writing of the research.

Victoria Newton contributed to the design, data collection, data analysis and writing of the research.

Lesley Hoggart contributed to the design, data analysis and writing of the research.

Mike Parker contributed to the design and data analysis of the research.

Elektra Lapavitsas provided research assistance.

Catherine Bannister helped to review the literature.

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